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ABSTRACT

The final part of a three part study of developmentally disabled persons in Washington State, this document focuses on clients of the Division of Developmental Disabilities (DDD), ages 19 through 26, who appeared to be eligible for DDD services but were not enrolled with the DDD (group C). Telephone interviews were conducted with parents of 55 developmentally disabled adults who were special education graduates and had a handicap consistent with DDD criteria, but were not enrolled in the DDD. Comparisons of group C Ss with DDD clients revealed that group C had higher functional skills and a higher representation in competitive employment. Further, families had a range of services and support available. Data did not support the assumption that there is a sizable population of unserved clients in need of DDD services. Less that 10% of the parents anticipated the need for family support or residential services through DDD, although 45% noted the likelihood of needing vocational training and/or job placement services. A description of methodology and a set of data tables are appended. (CL)

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Report:

DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS:

REPORT NO. 3

DIVISION OF ADMINISTRATION AND PERSONNEL

EC 182034

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DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS: REPORT NO. 3

Adults Who Appear Eligible for Services from the Division of Developmental Disabilities and Are Not Currently Enrolled with the Division

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March 1985

Program Research and Evaluation Section
Office of Research and Data Analysis
Department of Social and Health Services
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EXECUTIVE SUMMARY

In 1983 the Division of Developmental Disabilities (DDD), within the Washington State Department of Social and Health Services (DSHS) initiated a study of developmentally disabled persons in Washington State who have lived with their families. Earlier reports presented findings about two of the study groups, DDD clients living with their families (Group A) and DDD clients who were living with their families at age 18 and now live elsewhere (Group B). This report focuses on developmentally disabled persons, ages 19 through 26, who appeared to be eligible for DDD services and were not enrolled with DDD (Group C).

The goals of this phase of the study were to examine: (1) the differences and similarities between DDD clients and eligible developmentally disabled persons who are not DDD clients, (2) the sources of support and extent of unmet service needs among developmentally disabled persons not enrolled with DDD, and (3) the likelihood that these individuals would need DDD services in the future. Estimating the prevalence of DDD-eligible developmentally disabled persons in Washington was not a goal of this study.

Due to difficulties in accessing confidential information, a statewide random sample could not be selected. However, with cooperation from University of Washington research staff, telephone interviews were conducted with the parents of 53 developmentally disabled adults who: (a) were special education graduates from 11 school districts, including Spokane, Tacoma and Seattle and (b) were not enrolled with DDD but had a handicapping condition consistent with DDD eligibility criteria. Results concerning these individuals are compared with data about DDD clients of the same age from Groups A and B. Major findings are summarized below.

<u>How do these developmentally disabled persons (Group C) compare with DDD clients?</u>

- These individuals were reported to have higher functional skills than DDD clients: more independence in personal care and independent living activities, higher communication and social skills, greater ability to manage risk situations, fewer dangerous behavior problems, and less need for home and community supervision.

- They were less likely to participate in any scheduled work, school, or training activities: 40% (Group C) versus 69% (Group A) and 85% (Group B).

- Employed persons in Group C (34%) were more likely to work in competitive settings, to work more hours, and to earn higher wages than employed DDD clients (31%) for whom data were available.

What sources of support do these families use, and do they have unmet needs?

- Over three-fourths (81%) of the families had someone to care for their relative in an emergency, usually for as long as needed.

- Within the past year 30 percent had received family support services similar to those provided by DDD (e.g., attendant care, special equipment), most often respite care provided by family or friends.

- One-third expressed a need for one or more family support services similar to those provided by DDD, most often speech therapy (23%).

- Thirty-four percent indicated that their relative was receiving Supplemental Security Income.

- Study findings do not support the assumption that there is a sizable population of unserved persons in this age group (19-26) now in need of DDD services.

Do these parents anticipate needing DDD services in the future?

- Less than 10 percent considered it very likely that they would need any family support or residential services through DDD within the next two years.

- Forty-five percent considered it very likely that their relative would need vocational training and/or job placement services within the next two years.

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CHAPTER I. STUDY OVERVIEW

Background

This is the third in a series of three reports which describes developmentally disabled persons in Washington State. The first report described clients of the Division of Developmental Disabilities (DDD) who were living with their families (Group A). The second study concerned DDD clients who had lived with their families until at least 18 years of age and had since moved away from home (Group B). This report describes developmentally disabled persons who appeared to be eligible for DDD services and were not clients of the Division (Group C).

The goals of this phase of the study were to examine: (1) the differences and similarities between DDD clients and eligible developmentally disabled persons who are not DDD clients, (2) the sources of support and extent of unmet service needs among developmentally disabled persons not enrolled with DDD, and (3) the likelihood that these individuals would need DDD services in future. Estimating the prevalence of DDD-eligible developmentally disabled persons in Washington was not a goal of this study.

To achieve these goals, data were collected about the demographic characteristics and history of Group C members, their functional abilities, needs for support, current health, and their daily living experiences. For those who were living at home, there were items about the family living situation--family interactions and adjustments to the individual's presence in the family home. Additional information was collected about resources and services used, and parents' goals and expectations for their developmentally disabled family member.

Identification of Study Group C

The preferred approach, which would identify most of this population, was to access school records of former special education students throughout the state. However, when this proved infeasible because of restrictions on accessing confidential information, access to a portion of this group was obtained with the assistance of the University of Washington Experimental Education Unit (EEU). While reviewing student records of former special education graduates in 11 school districts, 1/ EEU research staff identified individuals who appeared to be eligible for DDD services. To be considered DDD-eligible, school records had to identify a student as mildly to profoundly mentally retarded (with I.Q. below 69), multihandicapped, or deaf-blind. Then, in the course of interviewing these parents for a University-sponsored study, EEU research staff requested parents' permission to release their names and other identifying information to the DSHS research project. Of the 187 persons who met the criteria of apparent DDD eligibility, 33 refused permission to release information to DSHS, and 80 were already enrolled with the Division.

1/ These included Everett, Tacoma, Seattle, Spokane, Vancouver, Evergreen, Battleground, Camas, Washougal, Ridgefield and LaCenter School Districts.

This rigorous screening process identified 74 individuals with the following characteristics: a) classified as mentally retarded, multihandicapped, or deaf-blind for special education services; b) graduated between 1979 and 1984 from one of the 11 school districts cited; c) had families that could be contacted by telephone and agreed to release their names to DSHS; and d) were not listed as current DDD Field Services clients. Parent interviews were completed for 53 of these individuals. (Detailed information about study methods appears in Appendix A.)

Some demographic information about Group C was collected from school data sheets compiled by the Unversity of Washington research staff, but most was obtained through telephone interviews with the nearest relative or guardian ("parent") of each member of the study group. Because this was not a random sample and the size of the study group was small, caution should be exercised in generalizing these findings. The descriptive information about this study group may be considered illustrative, but not necessarily representative, of the population of persons in the state who are eligible for DDD services and not enrolled with the Division. Also, when comparisons are made among study groups it should be noted that the data for Groups A and C reflect the year before the interview, whereas the Group B data characterize the circumstances during the year before the clients moved from home.

The next chapter summarizes the characteristics, activities and resources of Group C individuals and their families and compares them with data for Group A and B clients of about the same age. The last chapter describes parents' satisfaction with the status quo, as well as plans and provisions which have been made for the future. The parents' opinions about the likelihood of needing DDD services in the future are also presented in the final chapter.

CHAPTER II. CHARACTERISTICS, ACTIVITIES AND SUPPORTS FOR GROUP C IN COMPARISON WITH GROUPS A AND B

Information from parent interviews was used to develop a profile of Group C -- 53 young adults, aged 19 through 26, who appeared to be eligible for services from DDD and were not DDD clients. This chapter summarizes the major characteristics and activities of these individuals and describes the supports for their families. Findings are compared with data about the DDD clients studied previously: 264 Group A clients whose ages were similar to Group C and 224 Group B clients who were of comparable ages during the year before they moved from home.

Demographic Data

Demographic characteristics of DDD clients and other developmentally disabled persons (Group C) are summarized in Table 2.1. The members of Group C resembled the DDD clients in the following characteristics: (a) sex, (b) educational history, (c) family income, (d) number of parents at home, and (e) parents' health. The average family sizes were also similar among the three groups: 3.8 (Group A), 4.5 (Group B), and 3.9 (Group C).

Whereas the parents' age and employment status appeared similar for Groups A and C, they differed significantly from Group B parents (Table 2.1). According to parent reports of circumstances during the year before their relative moved from home, Group B parents were more likely to be in good health and have full-time employment than parents in the other two groups.

Other differences among groups--in the distribution of urban versus non-urban dwellers and in the types of residential settings where individuals lived--reflect the procedures and criteria used in identifying the study groups.

Developmental Disabilities and Health

Less than five percent of Group C clients had developmental disabilities other than mental retardation, which was lower than among DDD clients (Table 2.2). According to levels of retardation documented in school records (for Group C) or DDD records (for Groups A and B), Groups B and C were quite similar: Nearly two-thirds of their members were mildly retarded or above. Persons with moderate to profound retardation were more prevalent in Group A (48%) than Groups B and C (about 37%).

TABLE 2.1

INDIVIDUAL AND FAMILY DEMOGRAPHICS
BY STUDY GROUP

Individual Demographics	Group A %	Group A n	Group B %	Group B n	Group C %	Group C n
Sex:						
Female	42	(111)	49	(109)	43	(23)
Male	58	(151)	51	(113)	57	(30)
Locale:						
Urban a/	79	(209)	73	(162)	100	(53)
Non-urban	21	(55)	27	(60)	0	(0)
Current residential setting:*						
Independent living	0	(0)	39	(85)	19	(10)
With family	100	(264)	0	(1)	76	(40)
Regular group home	0	(0)	39	(85)	4	(2)
Other group facilities (non-DDD) b/	0	(0)	16	(34)	0	(0)
Institutions for mentally retarded persons (IMRs, RHCs)	0	(0)	6	(14)	0	(0)
Other (unspecified)	0	(0)	0	(0)	2	(1)
Current or most recent school program:						
Special school/facility (segregated)	28	(74)	27	(31)	34	(18)
Special classes (regular school)	61	(159)	56	(65)	47	(25)
Some/all regular classes	8	(21)	9	(10)	19	(10)
Other	3	(6)	8	(9)	0	(0)
Family demographics						
Annual income:						
Less than $10,000	25	(56)	18	(32)	12	(6)
$10,000 - 20,000	28	(65)	36	(65)	31	(16)
$20,000 - 40,000	38	(87)	39	(72)	46	(24)
Over $40,000	9	(20)	8	(14)	12	(6)
Family composition:						
2 parents	80	(209)	89	(197)	83	(44)
1 parent	20	(53)	11	(25)	17	(9)
Parent employment:*						
At least 1 parent works full-time	63	(165)	79	(177)	62	(33)
No parent works full-time	37	(97)	21	(46)	38	(20)
Parent health:						
At least 1 parent in good to excellent health	85	(221)	90	(198)	81	(43)
No parent in good to excellent health	15	(40)	10	(23)	19	(10)
Parent age:*						
At least 1 parent less than 60 years old	82	(216)	90	(198)	83	(44)
No parent less than 60 years old	18	(46)	10	(23)	17	(9)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

a/ "Urban" means living in 1 of 10 Washington counties located within a Standard Metropolitan Statistical Area, as identified in the 1980 Census: Benton, Clark, Franklin, King, Pierce, Snohomish, Spokane, Thurston, Whatcom, and Yakima Counties.

TABLE 2.2

NATURE AND EXTENT OF DEVELOPMENTAL DISABILITY
BY STUDY GROUP

	Group A		Group B		Group C	
	%	n	%	n	%	n
Developmental disability:*						
Mental retardation (MR) only	71	(188)	70	(151)	90	(48)
MR with another disability	17	(44)	17	(37)	4	(2)
MR with no further information	6	(15)	5	(10)	2	(1)
Other disability (without MR)	7	(17)	9	(19)	4	(2)
Documented level of mental retardation: a/*						
Borderline	29	(61)	32	(55)	0	(0)
Mild	22	(48)	30	(52)	63	(31)
Moderate	32	(69)	24	(41)	24	(12)
Severe-Profound	16	(35)	13	(27)	12	(6)

Note. Documented in DDD case records (Groups A and B) and school records (Group C).

a/ This excludes persons who were not mentally retarded or whose level of retardation was unknown.

* $p < .05$

Available parent data suggests that most individuals in Group C were healthy and had few unmet health care needs. Within Group C, 85 percent were characterized as in good or excellent health, 12 percent in fair health, and 4 percent in poor health. Most Group C members had no unmet physical health needs (85%), no unmet mental health needs (81%), and were receiving adequate dental care (74%). Of the 26 percent not receiving adequate dental care, most often this was attributed to limited financial resources. In comparison, the reported health status and needs for care were similar among DDD clients and other developmentally disabled persons.

Individual Functioning

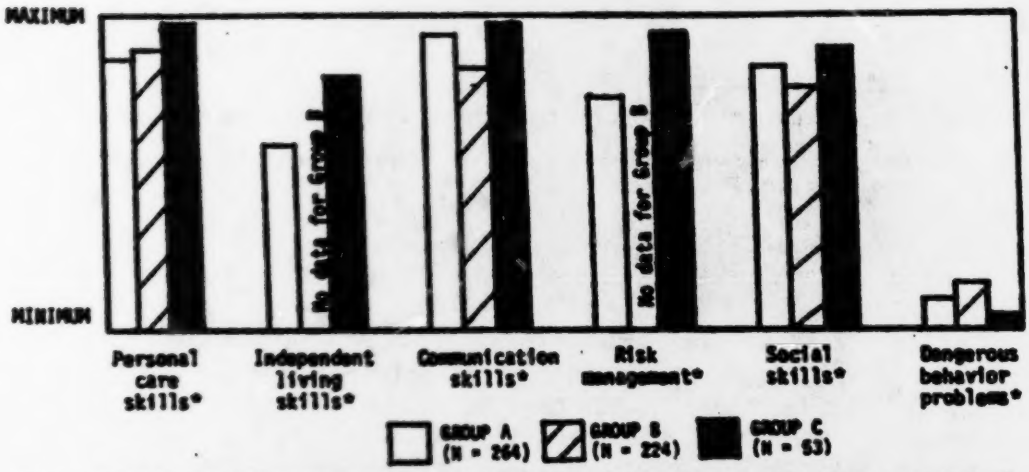
Over the past decade there has been a trend away from reliance upon general intelligence measures and toward assessment of individuals' actual functional performance in a range of areas. The parent interview included a series of items about individual functioning in the following areas: personal care activities (i.e., self-help), independent living activities (e.g., shopping, meal preparation), communication, social interactions, and risk management (i.e., personal safety). Additional items covered the presence of dangerous behavior problems. Parents were asked to describe the client's actual performance, rather than to estimate his/her capabilities or motivation.

For each personal care and independent living activity, parents were asked to describe the amount of help their relative usually needed to perform the activity: none, some, a lot, or total. Questions regarding communication and social interactions required parents to select the response which best characterized the individual's typical behavior. Risk management and behavior

problems were measured by a series of yes/no questions. For each area of individual functioning a summary index was constructed from related items. Figure 2.1 compares individual functioning across study groups, based on average index scores. (See Appendix B for a description of each index.)

FIGURE 2.1

COMPARISON OF INDIVIDUAL FUNCTIONING
USING TRANSFORMED INDEX SCORES
BY STUDY GROUP



Note. Transformed index scores represent the average index score expressed as a percent of the maximum possible score for each index. See Tables B.1 - B.6 for detailed information about each index. These data pertain to the year the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A & C).

*$p < .05$

The members of Group C were generally functioning at higher levels than the DDD clients. As illustrated in Figure 2.1 those persons not enrolled with the Division had relatively higher personal care and independent living skills, as well as communication and social skills. Group C members were also considered more capable of managing situations involving personal risk and safety such as giving personal information, calling for emergency help, and knowing what to do in case of fire. In addition, persons in Group C were least likely to have dangerous behavior problems (causing physical harm to self or others or destroying property).

Consistent with their higher functioning, members of Group C reportedly required significantly less home and community supervision than their counterparts in Groups A and B. Those needing no home supervision comprised 48 percent of Group C, 20 percent of Group A, and 17 percent of Group B. Similarly, 43 percent of Group C reportedly needed no supervision in the community as compared to 21 percent and 19 percent for Groups A and B.

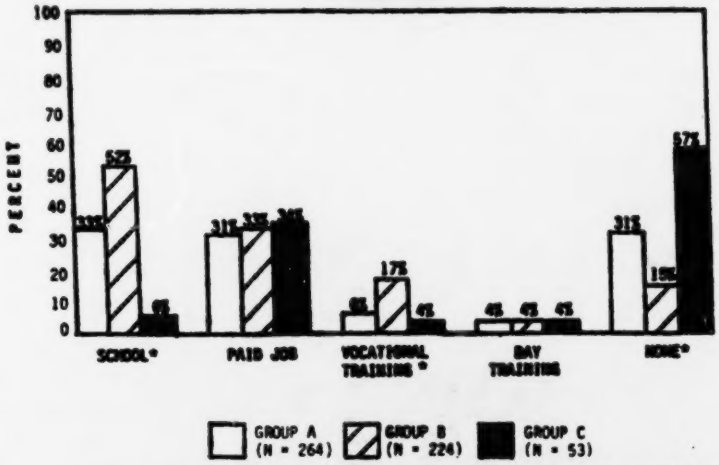
Individual/Family Activities 2/

There are several differences between DDD clients and other developmentally disabled persons in their leisure activities and regularly scheduled activities, (i.e., work, school, and training programs). In contrast with DDD clients, members of Group C participated in more community activities such as shopping, going to restaurants, and playing sports (Table B.7). Although their numbers of friends were similar, more persons in Group C had had friends over within the past month (63% versus 46% of Group A). In both Groups A and C, the majority of persons went places in the community by walking/using a wheelchair and taking the bus (Table B.8).

On the other hand, persons in Group C were less likely than DDD clients to participate in scheduled activities. As shown in Figure 2.2, significantly more DDD clients attended school and vocational training programs, and significantly more members of Group C did not participate in any scheduled activities. Participation in day training programs and employment rates were similar for all groups.

FIGURE 2.2

PARTICIPATION IN WORK, SCHOOL, AND TRAINING BY STUDY GROUP



Note. Total of percentages reported within each study group exceeds 100% due to participation in more than one program. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

2/ Some of these data were not available for Group B. When Group B data are presented, they pertain to the year before the client moved away from home.

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Group C members also spent less time in scheduled activities than either Group A or B. The total hours per week individuals spent in scheduled activities were computed for each group (Table 2.3). Weekly averages dropped from 26 hours (Group B) to 18 hours (Group A) to 12 hours (Group C). Overall, 72 percent of Group C members spent less than 25 hours per week in scheduled activities, versus 53 percent of Group A and 30 percent of Group B. 3/

TABLE 2.3

TOTAL HOURS PER WEEK SPENT IN WORK, SCHOOL, AND TRAINING ACTIVITIES BY STUDY GROUP*

	A (N=252) %	B (N=202) %	C (N=53) %
0	31	17	57
1-9	6	2	2
10-24	16	11	13
25-34	38	49	9
35 and above	9	21	19

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

The employment rates were similar for each group (about 30%), but there were marked differences in type and extent of employment between Groups A and C. Employed persons in Group C were more likely to work in competitive settings, to work more hours per week, and to earn higher wages than their counterparts in Group A (Table 2.4).

3/ "Habilitation Standards to House Bill 270" (Division of Developmental Disabilities, November 1983) states that "...every eligible person will have access to at least five hours of habilitation per day, five days a week, away from where they live." Habilitation services are defined as "employment, education, vocational habilitation, therapy and related services," which corresponds with the "scheduled activities" discussed in the current report.

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TABLE 2.4

EMPLOYMENT DATA
FOR GROUPS A AND C*

	Group A		Group C	
	%	n	%	n
Employment status:				
No employment	69	(181)	66	(35)
Sheltered employment	26	(70)	11	(6)
Competitive employment	5	(12)	23	(12)
Of those employed,	X	n	X	n
Average number of hours worked per week:				
In sheltered employment	25	(66)	34	(6)
In competitive employment	22	(11)	26	(12)
Total	25	(77)	29	(18)
Average monthly earnings:				
In sheltered employment	$60	(66)	$196	(6)
In competitive employment	$216	(12)	$318	(11)
Total	$84	(78)	$275	(17)

* No statistical analyses are reported due to small number of cases involved.

Supports for the Family

The percentages of parents who reported having someone to care for their developmentally disabled relative in an emergency were similar across groups: 86 percent of Group A, 78 percent of Group B, and 81 percent of Group C. However, Group C families were more likely to have someone available for as long as necessary (55% versus 42% for Group A and 34% for Group B). Group C families whose developmentally disabled relatives lived with them (n=40) were asked how much they felt this restricted them from working outside the home; 62 percent reported no restrictions, compared to 48 percent for Groups A and B.

Parents in Group C were asked whether or not within the past year they had received family support services similar to those provided by DDD (e.g., respite care, attendant care, special equipment). Except for family counseling, the distribution of parents who reported receiving and needing each family support service were similar for Group C families and families of DDD clients (Table 2.5). Within Group C the most frequently received service was respite care (25%), generally provided by family or friends. Less than 10 percent of these families had received special equipment, therapy or family counseling, and none had received attendant care or home remodeling assistance. An index of family support services received (Table B.9) showed that 30 percent of Group C families had received at least one family support service within the past year.

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TABLE 2.5

NEED FOR FAMILY SUPPORT SERVICES
BY STUDY GROUP

	Group A		Group B		Group C	
	%	n	%	n	%	n
Respite care: a/						
Not received, but needed	13	(35)	11	(18)	12	(5)
Not received, not needed	65	(170)	66	(105)	62	(25)
Received, but inadequate	3	(9)	6	(9)	0	(0)
Received and adequate	18	(46)	16	(26)	25	(10)
Special equipment:						
Not received, but needed	4	(11)	6	(9)	0	(0)
Not received, not needed	95	(250)	92	(148)	94	(48)
Received, but inadequate	0	(0)	1	(1)	0	(0)
Received and adequate	1	(2)	1	(2)	6	(3)
Home remodeling:						
Not received, but needed	7	(18)	6	(10)	0	(0)
Not received, not needed	92	(243)	94	(151)	100	(52)
Received, but inadequate	0	(0)	0	(0)	0	(0)
Received and adequate	1	(2)	0	(0)	0	(0)
Therapy:						
Not received, but needed	37	(96)	33	(52)	24	(12)
Not received, not needed	58	(152)	57	(90)	68	(34)
Received, but inadequate	2	(4)	6	(9)	0	(0)
Received and adequate	3	(8)	4	(6)	8	(4)
Attendant care:						
Not received, but needed	7	(19)	7	(12)	0	(0)
Not received, not needed	89	(234)	92	(148)	100	(52)
Received, but inadequate	1	(2)	0	(0)	0	(0)
Received and adequate	3	(8)	1	(1)	0	(0)
Family counseling:*						
Not received, but needed	17	(43)	27	(43)	6	(3)
Not received, not needed	79	(205)	68	(109)	92	(46)
Received, but inadequate	1	(2)	3	(5)	0	(0)
Received and adequate	3	(9)	2	(3)	2	(1)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C). Parents in Groups A and B were asked if these services were provided through DDD; Group C parents were asked if they received these services from any source whatsoever.

a/ For Group C this was only asked of parents whose relative was living at home.

*p < .05

Few Group C families reported having unmet needs for support services (Table 2.5). Of those who were not receiving family support services, the majority said they did not need them. The most frequently reported need was speech therapy (23%).

One form of support that Group C individuals were less likely to receive than DDD clients was Supplemental Security Income (SSI): 34 percent of Group C were receiving SSI versus 63 percent of Group A. The sources of these data were different for each group--DD Specialist reports for Group A and parent reports for Group C. Nevertheless, even allowing for possible underreporting by parents, these differences appear to be significant.

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Prior Experience with DDD

Just over half the parents (55%) said they had read or heard about DDD services within the past two years, most often through a public agency. Thirteen percent indicated that their relative was a former DDD client. Another 17 percent said that he or she was currently enrolled with the Division, although none of these names were on the client lists provided by DDD Field Services staff. 4/ Because many parents seemed to confuse DDD with other resources (e.g., the Division of Vocational Rehabilitation), the accuracy of these data is questionable. When parents were asked why their relative was not (or no longer) a DDD client, the most frequent answers were: (1) that they did not believe their relative was eligible for DDD services (40%) and (2) that they did not need DDD services (21%).

Summary of Comparisons

The emergent profile of these developmentally disabled persons does not support the assumption that there is now a sizable population of unserved persons (ages 19-26) in need of DDD services. 5/ On the contrary, Group C data suggests that the Division is serving a population which is more functionally disabled than other developmentally disabled persons, e.g., with lower skills across six functioning areas and greater needs for supervision. The incidence of health care needs and needs for family support services were similar for DDD clients and other developmentally disabled persons. In contrast with DDD clients, significantly fewer Group C members participated in regularly scheduled work, school, and training activities. However, the employment rates were similar across groups, and the likelihood of competitive employment was higher among persons not enrolled with the Division.

4/ Persons who were not listed as current DDD Field Services clients may have been former DDD clients (whose names had been deleted), new DDD clients (whose names had not yet been added), or clients of another DSHS program (confused with DDD).

5/ The DDD Master Plan (public review draft, June 1984, page 2-10) estimates that "the program appears to be serving about 45 percent, or just under half, of the severely developmentally disabled persons living in Washington State."

CHAPTER III. INDIVIDUAL STATUS--CURRENT AND FUTURE

The final research question posed for Group C was "How likely are they to become clients in the future?" Parents were asked to describe their satisfaction with their relative's current circumstances and any plans and arrangements that had been made for the future. While discussing future plans, families were given brief descriptions of services available through DDD; they were asked about the likelihood that their developmentally disabled relative would need these services within the next two years.

Satisfaction with Current Circumstances

Families were asked their opinions about their relative's current circumstances. For respondents whose developmentally disabled relatives did not live with them (24%), it was important to confirm that they were knowledgeable about their relative's current status: All had spoken with their relative within the past three months and, with one exception, had been in contact at least weekly.

Fifty percent of the families interviewed reported having no major concerns about their relative's current living arrangement or current weekday routine (e.g., job, school, training program). Those who expressed concerns about current living arrangements for their developmentally disabled relative (31%) were mostly parents whose developmentally disabled relative lived at home. Most often families were concerned about finding a semi-independent living situation for their relative which provided limited support/supervision. Thirty-four percent of the families expressed concerns about their relative's current weekly routine, over half of which pertained to his or her having no job or training program.

Over half of the parents (60%) reported having additional concerns about their relative, yet many (29%) simply elaborated upon residential and/or vocational concerns already reported. Other concerns included what would happen to their relative when the parent(s) died (12%) and how to promote continued growth and independence for their relative (10%). These findings were compared with concerns about Group A clients, as reported by their parents and DD Specialists: The incidence and nature of concerns about developmentally disabled adults were similar, regardless of their status as DDD clients.

Plans and Arrangements for the Future

When asked their preference for a permanent residential setting for their relative, 58 percent of Group C parents indicated the status quo--which, for the majority, meant continued living at home. About one-fourth of the parents expected their relative to move within the next two years. In all but one of these instances the developmentally disabled individual was living at home at the time. Similar results were obtained for DDD clients living at home: 46 percent of the parents preferred that their relative remain at home and 31 percent anticipated a move within two years.

Parents also indicated the type of weekday program they deemed most appropriate for their relative within the next two years: most often sheltered employment (62%), competitive employment (22%), or post-high school education (12%). In contrast with parents of DDD clients (Group A only), these parents were less likely to identify sheltered employment as a short-term vocational goal for their relative. Table 3.1 shows the relationship between families' short-term vocational goals for their relatives and the scheduled activities in which these persons were participating.

TABLE 3.1

INDIVIDUAL'S CURRENT PARTICIPATION IN WORK, SCHOOL, OR TRAINING BY THE FAMILY'S VOCATIONAL GOAL FOR THEM

The individual's current scheduled activities:	The family's vocational goal for their developmentally disabled relative (within the next two years): Competitive employment (N=11) %	Sheltered work/training a/ (N=32) %	Post-high school education (N=6) %	Other (volunteer work) (N=1) %
Competitive employment	54	9	33	0
Sheltered employment	18	12	0	0
Vocational training	9	3	0	0
Post-high school education	0	0	50	0
Day program	9	3	0	0
None	18	72	33	100

Note. The total percentage in each column may exceed 100 percent due to some individuals, who participated in more than one scheduled activity.

a/ The short-term goal "sheltered work or work-related training" encompasses both sheltered employment and vocational training.

The parents were asked about any arrangements already made to provide for their relative's future. Sixty-two percent of the families had made some financial arrangement for their relative, most often inheritance provisions (53% overall). The percentages of families who had not made financial provisions for their relative were similar across study groups: 33 percent (Group A), 40 percent (Group B), and 38 percent (Group C).

Nearly half of the Group C families (48%) had arranged for someone to supervise their developmentally disabled relative upon the parents' death or disability: 30 percent (overall) had assigned a guardian and 17 percent had designated a sponsor/advocate. The percentage of families without such arrangements (52%) was higher compared to Group A (35%) or Group B (40%).

Likelihood of Future Involvement with DDD

Three types of DDD services were described to parents: (1) family support services including respite care, attendant care, home remodeling, special equipment, and behavior management training; (2) residential facilities and support programs including staff support for individuals living on their own, and (3) habilitation services to encourage individual independence in

the community, e.g., job placement, work-related training, therapy, and services to develop life skills. Families were then asked to indicate the likelihood of their needing each type of service within the next two years: very likely, somewhat likely, or not at all likely. As shown in Table 3.2, less than 10 percent considered it very likely that they would need family support or residential services through DDD. On the other hand, 45 percent thought it very likely that their relative would need habilitation services through the Division.

TABLE 3.2

LIKELIHOOD THAT PERSONS IN GROUP C WOULD NEED DDD SERVICES WITHIN THE NEXT TWO YEARS (N=53)

	Family Support Services a/	Residential Assistance	Habilitation Services
	%	%	%
Very likely	8	9	45
Somewhat likely	13	6	36
Not at all likely	53	81	15
Not applicable	24	0	0
Don't know	2	4	4

a/ Only asked of families whose relative was living at home.

APPENDIX A

METHODOLOGY FOR GROUP C

Sample Selection

Given the extensive safeguards which protect the confidentiality of public agency records (including school records), a statewide random sample of developmentally disabled individuals who were not DDD clients could not be identified. The preferred approach, which would identify most of this population, was to access school records of former special education students throughout the state. However, when this proved infeasible, project staff obtained access to a portion of this group with the assistance of the University of Washington Experimental Education Unit (EEU). EEU research staff, while interviewing parents of special education graduates in selected school districts, requested parents' permission to release their names and other identifying information to the DSHS research project.

The identification of Group C is summarized in Table A.1. The screening process began with University of Washington research staff who examined thousands of school records and generated a list of 1,841 special education students who were graduated between 1979 and 1984 from Tacoma, Seattle, Spokane, Everett, Evergreen, Vancouver, Battleground, Camas, Washougal, Ridgefield, and LaCenter School Districts. (These school districts were included because they had already established working agreements with the EEU.) Research staff were unable to contact 1,061 from this initial list, 6/ and 61 refused to be interviewed. Of the 719 interviews completed by the EEU staff, only 187 graduates appeared to be eligible for DDD services, based on information in their school records--i.e., the student was classified as mildly to profoundly mentally retarded (with I.Q. below 69), multi-handicapped or deaf-blind.

Certainly there were some DDD-eligible special education graduates of these school districts who were not identified by this screening procedure. There were DDD eligible persons among those whom the EEU staff were unable to contact. Students classified as sensory or orthopedically impaired were excluded, yet some may have been eligible for DDD services. The study group selection method also excluded persons from private schools, high school drop-outs, students with incomplete records, and developmentally disabled individuals who were graduated or completed special education prior to 1979.

Of the 187 persons who met these screening criteria, 33 refused to allow the EEU to release information to DSHS, and 80 were already enrolled as DDD clients. DSHS staff attempted telephone interviews with the remaining 74 persons who were not DDD clients and appeared to be eligible for DDD services: 9 of these families could not be contacted, 12 refused to be interviewed, and 53 parent interviews were completed. In addition to data from telephone interviews, limited demographic data were collected from school data sheets compiled by the EEU research staff.

6/ Because these student records were one to five years old, the family addresses and telephone numbers cited were frequently out-of-date.

TABLE A.1

IDENTIFICATION OF GROUP C MEMBERS
(PERSONS WHO APPEARED ELIGIBLE FOR DDD SERVICES
AND WERE NOT ENROLLED AS DDD CLIENTS)

Total special education graduates, 1979-1984 from 11 school districts a/	1,841
Could not be contacted	-1,061
Refused interview	-61
Total interviews completed by U. of Wash.	719
Excluded as not DDD-eligible	-532
Total DDD-eligible persons interviewed by U. of Wash. b/	187
Refused to release information to DSHS	-33
Total names released to DSHS	154
Excluded as current DDD clients	-80
Total interviews attempted by DSHS research staff	74
Could not be contacted	-9
Refused interview	-12
Total interviews completed by DSHS research staff	53

a/ These included Everett, Tacoma, Seattle, Spokane, Vancouver, Evergreen, Battleground, Camas, Washougal, Ridgefield and LaCenter School Districts.

b/ Based on school records indicating one of the following handicapping conditions, as identified by the Office of the Superintendent of Public Instruction: mild, moderate, or severe mental retardation; multi-handicapped; deaf-blind.

Since this was not a random sample and the size of the study group was small, caution should be exercised in generalizing these findings. Descriptive information about this study group may be considered illustrative, but not necessarily representative, of the population of persons in the state who are eligible for DDD services and not enrolled with the Division.

Data Collection

Data on Group C were obtained from school records by University of Washington staff and telephone interviews with relatives or guardians by DSHS staff. Telephone interviews were conducted by a member of the interview team that conducted the Group A and Group B telephone interviews, so she had already received extensive training and experience interviewing parents of developmentally disabled adults. Major topics addressed during the interview included the demographic characteristics and history of these individuals, their functional abilities, needs for support, current health, and their daily living experiences. For those who were living at home, there were items about the family living situation--family interactions and adjustments to the client's continued presence in the family home, resources and services used, and goals and expectations for the developmentally disabled family member.

Reliability

Many of the results from Groups A and B reliability tests were utilized to enhance Group C efforts. Consequently, fewer reliability measures were necessary during data collection for Group C. At the close of each interview the interviewer rated the respondent's attentiveness, comprehension, and overall reliability. Data from respondents with two or more "poor" ratings were to be excluded from analysis, but the situation did not arise.

Data Analysis

The data were keyed onto tape at DSHS headquarters in Olympia. The raw data were then run through range and logic edit programs and corrected before system files were created using SPSS-X (Statistical Package for the Social Sciences, Version X). The Group C system file was then merged with the Group A and Group B system file into one system file to facilitate comparative analyses among Groups A, B and C.

Some data reduction was performed by constructing summary indices for related item subsets. Two types of indices were created. The first type, which will be referred to as "count indices", were made up of dichotomized variables, (e.g., yes = 1, no/don't know = 0). The indices were constructed by counting the number of "yes" responses (value = 1) across all items of the index for each case. The maximum index score is equal to the number of items in the index; the lowest index score is zero. The count indices included communication skills, risk management skills, dangerous behavior problems, community activity, community mobility, and family support services.

The second type of index was made up of items with more than two response values, (e.g., never = 1, sometimes = 2, often = 3). In this case the response values were summed across all items in the index for each case, with item means substituted for items with missing values. For this type of index the maximum index score is equal to the sum of the highest values of all items in the index. The summed indices were personal care skills, independent living skills, and social skills.

A reliability analysis of index components was performed by computing Cronbach's alpha test for internal homogeneity, which is a standard test of internal consistency among items used to construct an index. 7/ When alpha is squared it becomes the coefficient of reliability which equals the proportion of variance shared by all items used to construct the index. It was decided that if items shared at least 49 percent of the total variance then the internal consistency of the index was sufficient for the purposes of this study. Thus, indices with an alpha of .70 or greater were used in analysis. All items used to construct each of the indices discussed in the text are presented in Appendix B.

7/ Cronbach, L. "Coefficient Alpha and the Internal Structure of Tests". Psycometrika, XVI. 1951, pp. 297-344.

The primary mode of data analysis was descriptive. Frequency distributions, means, and medians were generated across all data items. Tests of statistical significance between groups were performed on the data reported in the tables, unless otherwise stated. Data reported in percentage format were evaluated with the Chi-square statistic; data reported as averages were subject to a one-way analysis of variance and were evaluated with the F statistic. Relationships between selected items and indices were analyzed by computing Pearson correlation coefficients to determine the direction and strength of associations.

APPENDIX B

TABLES

Tables B.1 through B.9 present information about each of the summary indices described in the text: the items included in each index, the frequency of responses by study group, and other relevant statistics.

TABLE B.1

PERSONAL CARE SKILLS INDEX*

AMOUNT OF HELP NEEDED WITH PERSONAL CARE ACTIVITIES	A (N=264) %	B (N=224) %	C (N=53) %
Eating:			
4 - None	82	85	98
3 - Some	11	10	2
2 - A lot	4	2	0
1 - Total	3	2	0
Dressing:			
4 - None	74	74	94
3 - Some	15	13	6
2 - A lot	5	8	0
1 - Total	6	5	0
Using toilet:			
4 - None	77	81	100
3 - Some	13	10	0
2 - A lot	4	4	0
1 - Total	6	5	0
Bathing:			
4 - None	56	63	87
3 - Some	25	23	11
2 - A lot	10	4	0
1 - Total	9	9	0
Grooming:			
4 - None	30	33	66
3 - Some	47	47	34
2 - A lot	12	14	0
1 - Total	11	7	0
Moving about:			
4 - None	89	86	98
3 - Some	6	8	2
2 - A lot	0	3	0
1 - Total	5	3	0
Transferring:			
4 - None	92	91	100
3 - Some	2	4	0
2 - A lot	1	1	0
1 - Total	5	4	0

$\bar{X}$ Scores: 24.7 (A)
25.0 (B)
27.4 (C)

No. of items: 7
Range of values:
7 = minimum
28 = maximum

Standard deviation: 4.8 (A)
4.3 (B)
.9 (C)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

TABLE B.2

INDEPENDENT LIVING SKILLS INDEX*

AMOUNT OF HELP NEEDED WITH INDEPENDENT LIVING ACTIVITIES	A (N=264) %	C (N=53) %
Preparing meals:		
4-None	12	49
3-Some	25	19
2-A lot	32	21
1-Total	31	9
0-DK/NR	<1	2
Performing household tasks:		
4-None	35	79
3-Some	39	15
2-A lot	15	6
1-Total	10	0
0-DK/NR	0	0
Shopping:		
4-None	10	36
3-Some	22	32
2-A lot	32	23
1-Total	35	9
0-DK/NR	1	0
Using telephone:		
4-None	41	81
3-Some	17	13
2-A lot	11	4
1-Total	29	2
0-DK/NR	2	0
Using transportation:		
4-None	23	53
3-Some	23	26
2-A lot	22	15
1-Total	30	6
0-DK/NR	2	0
Managing money:		
4-None	3	21
3-Some	8	19
2-A lot	39	41
1-Total	51	19
0-DK/NR	0	0

No. of items: 6
Range of values:
6 = minimum
24 = maximum

$\bar{X}$ Scores: 13.9 (A)
19.1 (C)

Standard deviation: 4.6 (A)
3.6 (C)

* $p < .05$

TABLE B.3

COMMUNICATION SKILLS INDEX*

COMMUNICATION SKILLS	A (N=264) %	B (N=224) %	C (N=53) %
How individual communicates with others:			
1-Verbal	85	88	98
0-Non-verbal	15	12	2
0-Don't know	0	0	0
Ability to understand:			
1-Understands simple sentences	98	90	98
0-Does not understand simple sentences	0	9	2
0-Don't know	2	1	0
Ability to express self outside family:			
1-Uses simple sentences	100	76	94
0-Does not use simple sentences	0	24	6
0-Don't know	0	0	0

No. of items: 3
Range of values:
0 = minimum
3 = maximum

$\bar{X}$ Scores: 2.8 (A)
2.5 (B)
2.9 (C)

Standard deviation: .4 (A)
.3 (B)
.4 (C)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

TABLE B.4

RISK MANAGEMENT SKILLS INDEX*

DD INDIVIDUAL KNOWS	A (N=264) %	C (N=53) %
Name:		
1-Yes	92	100
0-No	7	0
0-Don't know	1	0
Address:		
1-Yes	89	100
0-No	10	0
0-Don't know	1	0
Phone number:		
1-Yes	86	100
0-No	11	0
0-Don't know	3	0
How to use public phone:		
1-Yes	42	83
0-No	48	11
0-Don't know	10	6
Pedestrian rules:		
1-Yes	72	92
0-No	23	6
0-Don't know	5	2
What to do if fire at home:		
1-Yes	71	87
0-No	21	6
0-Don't know	8	8

No. of items: 6
Range of values:
0 = minimum
6 = maximum

$\bar{X}$ Scores: 4.5 (A)
5.6 (C)

Standard deviation: 1.7 (A)
.8 (C)

* < p .05

TABLE B.5

SOCIAL SKILLS INDEX*

SOCIAL BEHAVIOR	A (N=264) %	B (N=224) %	C (N=53) %
Gets along with family:			
3 - Very well	64	53	72
2 - Adequately	30	30	23
1 - Not very well	6	16	6
0 - Don't know	0	0	0
Gets along with peers:			
3 - Very well	54	46	66
2 - Adequately	33	36	19
1 - Not very well	9	16	13
0 - Don't know	4	3	2
Behavior with persons outside the family:			
3 - Usually appropriate	74	72	81
2 - Sometimes appropriate	22	24	15
1 - Seldom appropriate	3	4	4
0 - Don't know	1	0	0

No. of items: 3
Range of values:
3 = minimum
9 = maximum

$\bar{X}$ Scores: 7.6 (A)
7.3 (B)
7.9 (C)

Standard deviation: 1.4 (A)
1.7 (B)
1.6 (C)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

TABLE B.6

DANGEROUS BEHAVIOR PROBLEM INDEX*

DD INDIVIDUAL HAS A SIGNIFICANT BEHAVIOR PROBLEM	A (N=264) %	B (N=224) %	C (N=53) %
Causing physical harm to others:			
1 - Yes	12	13	2
0 - No	88	86	98
0 - Don't know	0	1	0
Causing physical harm to self:			
1 - Yes	11	12	2
0 - No	89	87	98
0 - Don't know	<1	0	0
Destroying property:			
1 - Yes	11	13	6
0 - No	89	85	94
0 - Don't know	0	1	0
NONE OF THE ABOVE:	78	76	92

No. of items: 3
Range of values:
0 = minimum
3 = maximum

$\bar{X}$ Scores: .3 (A)
.4 (B)
.1 (C)

Standard deviation: .7 (A)
.8 (B)
.3 (C)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C).

* $p < .05$

TABLE B.7

COMMUNITY ACTIVITY INDEX*

DURING PAST MONTH THE DD INDIVIDUAL	A (N=264) %	C (N=53) %
Went to restaurant:		
1-At least once	88	89
0-Not at all	11	11
0-Don't know	<1	0
Went shopping:		
1-At least once	85	93
0-Not at all	14	7
0-Don't know	1	1
Went to movies/sports:		
1-At least once	51	64
0-Not at all	48	36
0-Don't know	1	0
Visited friends:		
1-At least once	77	89
0-Not at all	22	9
0-Don't know	1	2
Played sports:		
1-At least once	48	62
0-Not at all	50	34
0-Don't know	2	4
Walked or rode bike:		
1-At least once	64	81
0-Not at all	35	15
0-Don't know	1	4

No. of items: 6
Range of values:
0 = minimum
6 = maximum

$\bar{X}$ Scores: 4.2 (A)
4.8 (C)

Standard deviation: 1.3 (A)
1.3 (C)

* $p < .05$

TABLE B.8

COMMUNITY MOBILITY INDEX

MODE(S) OF TRANSPORTATION DD INDIVIDUAL USES	A (N=264) %	C (N=53) %
Walking or wheelchair:		
1-Yes	72	74
0-No	28	26
Riding bike or moped:		
1-Yes	34	47
0-No	66	53
Taking bus:		
1-Yes	60	55
0-No	40	45
Taking taxi:		
1-Yes	9	8
0-No	91	92
Driving oneself:		
1-Yes	3	13
0-No	97	87

No. of items: 5
Range of values:
0 = minimum
5 = maximum

$\bar{X}$ Scores: 1.8 (A)
2.0 (C)

Standard deviation: 1.0 (A)
.9 (C)

TABLE B.9

FAMILY SUPPORT SERVICES INDEX

DURING PAST YEAR THE DD INDIVIDUAL RECEIVED	A (N=264) %	B (N=224) %	C (N=53) %
Respite care:			
1 - Yes	21	16	19
0 - No	79	56	57
0 - Not applicable a/	0	28	24
Special equipment:			
1 - Yes	1	1	8
0 - No	99	70	92
0 - Not applicable	0	28	0
Money for remodeling:			
1 - Yes	1	0	0
0 - No	99	72	100
0 - Not applicable	0	28	0
Therapy:			
1 - Yes	6	7	8
0 - No	94	63	92
0 - Not applicable	0	28	0
Attendant care:			
1 - Yes	4	0	0
0 - No	96	72	100
0 - Not applicable	0	28	0
Counseling:			
1 - Yes	4	4	2
0 - No	95	68	98
0 - Not applicable	0	28	0
NONE OF THE ABOVE:	70	77	70

No. of items: 6
Range of values:
0 = minimum
6 = maximum

$\bar{X}$ Scores: .4 (A)
.3 (B)
.4 (C)

Standard deviation: .6 (A)
.6 (B)
.8 (C)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Groups A and C). Parents in Groups A and B were asked if the client received these services through DDD; Group C parents were asked if their relative received these services from any source whatsoever.

a/ Parents whose developmentally disabled relative lived elsewhere were not asked about family support services received.